

**National Health and Nutrition
Examination Survey 2005–2006**

**Documentation, Codebook,
and Frequencies**

**Hepatitis C Follow Up
Questionnaire**

**Survey Years:
2005 to 2006**

**SAS Transport File:
HCQ_D.XPT**



April 2008

NHANES 2005–2006 Data Documentation

Questionnaire Section: Hepatitis C Follow Up Questionnaire (HCQ_D)

First Published: April 2008

Last Revised: NA

Component Description

Participants 6 years and older testing positive for antibody to hepatitis C virus (anti-HCV) (LBXHC) are sent a report of findings (ROF) letter informing them of their HCV test result and encouraging them to follow up with a health care provider to determine if any other tests or procedures are needed. The follow-up phone questionnaire occurs 6 months after their examination (approximately 4-5 months after the ROF letter was mailed). The purpose of the questions is to assess what proportion of NHANES participants testing positive for infection with hepatitis C virus (HCV) already knew of their infection status, what they know about hepatitis C, and what actions they take after becoming aware of their infection status.

The HCV follow-up questionnaire is mentioned in the informed consent and also in the reporting letter for positive HCV letters. Trained interviewers contacted those participants with positive HCV results by telephone for an interview.

An automated system for managing calls (i.e., setting up appointments, tracking the calls to contact the participant, and reasons for refusal) is maintained in the Field Follow up Management System (FFMS). Responses to interview questions are keyed directly into the FFMS, a web based application of the Integrated Survey Information System (ISIS) software used for other NHANES components.

Participants who live in households with no telephones were sent a letter asking them to call a toll free number to answer a few questions about their Hepatitis C results.

Eligible Sample

Participants age 6 years and older testing positive for hepatitis C virus (anti-HCV) were eligible to participate. Parents or guardians are interviewed for participants with hepatitis C who are under the age of 18 years or adults who cannot respond for themselves.

Exclusion Criteria: Circumstances when communication or cognitive difficulties make it impossible for the participant to respond to questionnaire and a parent or guardian is not available to complete the interview would result in exclusion.

**Interview
Setting and
Mode of
Administration**

Bilingual (English and Spanish) trained interviewers contacted participants with positive hepatitis C results by telephone to request an interview. Call attempts were scheduled 6 months after the date of examination, approximately 4-5 months after participants receive the results notification letter. In order to determine what actions persons take with the information that they are infected, it is necessary to allow time to have initiated or implemented such actions after notification of infection. Therefore, the telephone interview occurs at least a few months after notification.

**Quality
Assurance &
Quality
Control**

The hepatitis C phone follow-up questions were evaluated in NCHS's Questionnaire Design Research Laboratory before the final questionnaire was approved by the NHANES Ethics Review Board (ERB).

**Data
Processing
and Editing**

N/A

**Analytic
Notes**

Combination of these data with other cycles is recommended when doing analysis. These data should not be used with sample weights to make national estimates due to small sample size and a response rate below 50%. (Only 34 out of 78 eligible were contacted and completed the questionnaire.)

The data should be linked to the laboratory data (Lab 02, LBXHC) by sequence number. Examples of reasons for non-response coded as "communication problem or cognitive impairment" may include hearing impairment, poor memory recall, and language barrier.

References

N/A

Locator Record

Title: Hepatitis C Follow Up Questionnaire (HCQ_D)

Contact Number: 1-866-441-NCHS

Years of Content: 2005–2006

First Published: April 2008

Revised: NA

Access Constraints: None

Use Constraints: None

Geographic Coverage: National

Subject: Hepatitis C Follow Up Questionnaire administered to survey participants who test positive for hepatitis C.

Record Source: NHANES 2005–2006

Survey Methodology: NHANES 2005–2006 is a stratified multistage probability sample of the civilian non-institutionalized population of the U.S.

Medium: NHANES Web site; SAS transport files

**National Health and Nutrition Examination Survey
Codebook for Data Production (2005-2006)**

**Questionnaire Section:
Hepatitis C Follow Up Questionnaire (HCQ_D)**

April 2008



SEQN	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	SAS Label
	Respondent sequence number
English Text: Respondent sequence number.	
English Instructions:	

HCASCST1	Target
	B(6 Yrs. to 150 Yrs.)
Hard Edits	SAS Label
	Interview Status Code
English Text: Interview Status Code	
English Instructions:	

Code or Value	Description	Count	Cumulative	Skip to Item
1	Complete	34	34	HCQ020
2	Partial	0	34	HCQ020
3	Not done	44	78	
.	Missing	0	78	

HCASCCT1		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		Reasons for Not Done		
English Text: Reasons the Interview was not done				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Unable to contact SP	37	37	End of Section
2	Refusal	6	43	End of Section
3	Communication problem or cognitive impairment	0	43	End of Section
4	SP expired	1	44	End of Section
5	Did not receive letter	0	44	End of Section
6	Other	0	44	End of Section
.	Missing	34	78	

HCQ020		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		Heard of Hepatitis C prior to letter?		
English Text: There are many types of hepatitis. Before receiving the letter with (your/SP's) test result, had you heard of hepatitis C?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	29	29	
2	No	5	34	
3	Heard of hepatitis, but not specifically hepatitis C	0	34	
7	Refused	0	34	
9	Don't know	0	34	
.	Missing	44	78	

HCQ030		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		First time told had Hepatitis C?		
English Text: Was the test result in our letter the first time you were told (you had/SP has) hepatitis C?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	16	16	HCQ070
2	No	18	34	
7	Refused	0	34	HCQ070
9	Don't know	0	34	HCQ070
.	Missing	44	78	

HCQ040		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		How long known infected?		
English Text: For about how long have you known that (you have/SP has) hepatitis C? Would you say ...				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	One year	4	4	
2	2 to 5 years	5	9	
3	More than 5 years	9	18	
7	Refused	0	18	
9	Don't know	0	18	
.	Missing	60	78	

HCQ060	Target			
	B(16 Yrs. to 150 Yrs.)			
Hard Edits	SAS Label			
	Reason first tested for Hepatitis C?			
English Text: Why were you first tested for hepatitis C? Was it because:				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	You donated blood?	1	1	
2	You had other blood tests done for a routine physical that showed you might have liver disease?	11	12	
3	You were sick with symptoms like fatigue, nausea, stomach pain, yellowing of the eyes or skin (known as jaundice)?	4	16	
4	You were exposed to blood while on the job?	0	16	
5	You or your doctor thought you were at risk of having hepatitis C?	0	16	
6	You had another reason?	2	18	
7	Refused	0	18	
9	Don't know	0	18	
.	Missing	60	78	

HCQ070	Target			
	B(6 Yrs. to 150 Yrs.)			
Hard Edits	SAS Label			
	Seen a doctor about test result?			
English Text: Did (you/SP) see a doctor or other health professional about (your/his/her) hepatitis C test result?				
English Instructions: Now I'm going to ask you some questions about what you have done (with SP) since finding out that (you have/your child has) hepatitis C. INTERVIEWER: If tested before NHANES, question refers to first test; otherwise refers to NHANES test.				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	28	28	HCQ090
2	No	6	34	
7	Refused	0	34	
9	Don't know	0	34	
.	Missing	44	78	

HCQ080	Target			
	B(6 Yrs. to 150 Yrs.)			
Hard Edits	SAS Label			
	Have a doctor's appointment?			
English Text: (Do you/Does SP) have an appointment to see a doctor or other health care professional about (your/his/her) hepatitis C test result?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	3	3	HCQ160
2	No	3	6	HCQ160
7	Refused	0	6	HCQ160
9	Don't know	0	6	HCQ160
.	Missing	72	78	

HCQ090	Target			
	B(6 Yrs. to 150 Yrs.)			
Hard Edits	SAS Label			
	Did doctor do additional tests?			
English Text: When (you/SP) saw a doctor or other health professional about (your/his/her) hepatitis C test results, did (you/he/she) have other blood tests to check how (your/his/her) liver is working?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	24	24	
2	No	2	26	
7	Refused	0	26	
9	Don't know	2	28	
.	Missing	50	78	

HCQ100	Target			
	B(6 Yrs. to 150 Yrs.)			
Hard Edits	SAS Label			
	What doctor told about test result?			
English Text: Which of the following statements describes most closely what (your/SP's) doctor told you about (your/his/her) hepatitis C result?				
English Instructions: Read each statement and check only one.				
Code or Value	Description	Count	Cumulative	Skip to Item
1	(You have/He/She has) hepatitis C and need(s) regular medical follow-up.	12	12	
2	You/He/She) tested positive for hepatitis C, but (do/does) not need to do anything or worry about it.	12	24	HCQ160
3	(You/He/she) really (don't/doesn't) have hepatitis C because a follow-up test showed that the positive test result was in error.	0	24	End of Section
4	Other	2	26	
7	Refused	0	26	
9	Don't know	1	27	
.	Missing	51	78	

HCQ110		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		Ever had a liver biopsy?		
English Text: Did (you/SP) have a liver biopsy (procedure to get a small piece of (your/his/her) liver through a needle)?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	7	7	
2	No	9	16	
7	Refused	0	16	
9	Don't know	0	16	
.	Missing	62	78	

HCQ121		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		Doctor advised about medications?		
English Text: Did (your/SP's) doctor or health care professional tell you that there are medicines that can be used to treat hepatitis C?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	12	12	
2	No	4	16	HCQ150
7	Refused	0	16	HCQ150
9	Don't know	0	16	HCQ150
.	Missing	62	78	

HCQ124		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		Doctor advised you should be treated?		
English Text: Did (your/SP's) doctor or health care professional tell you that your hepatitis C should be treated with medication such as Interferon and Ribavirin?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	8	8	HCQ130
2	No	4	12	
7	Refused	0	12	HCQ150
9	Don't know	0	12	HCQ150
.	Missing	66	78	

HCQ126A		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		Not treated: liver enzymes were normal?		
English Text: What reason did your doctor or health care professional give you when he/she told you that you should not be treated? Was it because your liver enzymes were normal?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	2	2	
2	No	2	4	
7	Refused	0	4	
9	Don't know	0	4	
.	Missing	74	78	

HCQ126B	Target			
	B(6 Yrs. to 150 Yrs.)			
Hard Edits	SAS Label			
	Not treated: did not have liver disease?			
English Text: What reason did your doctor or health care professional give you when he/she told you that you should not be treated? Was it because you did not have liver disease?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	0	0	
2	No	3	3	
7	Refused	0	3	
9	Don't know	0	3	
.	Missing	75	78	

HCQ126C	Target			
	B(6 Yrs. to 150 Yrs.)			
Hard Edits	SAS Label			
	Not treated: not need to do anything?			
English Text: What reason did your doctor or health care professional give you when he/she told you that you should not be treated? Was it because you do not need to do anything for hepatitis C?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	0	0	
2	No	3	3	
7	Refused	0	3	
9	Don't know	0	3	
.	Missing	75	78	

HCQ126D	Target			
	B(6 Yrs. to 150 Yrs.)			
Hard Edits	SAS Label			
	Not treated: can be treated later?			
English Text: What reason did your doctor or health care professional give you when he/she told you that you should not be treated? Was it because you can wait to be treated at a later time?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	2	2	
2	No	0	2	
7	Refused	0	2	
9	Don't know	1	3	
.	Missing	75	78	

HCQ126E	Target			
	B(6 Yrs. to 150 Yrs.)			
Hard Edits	SAS Label			
	Not treated: no reason given			
English Text: What reason did your doctor or health care professional give you when he/she told you that you should not be treated? Was it because... No reason specified.				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	1	1	
2	No	3	4	
7	Refused	0	4	
9	Don't know	0	4	
.	Missing	74	78	

HCQ130		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		Treated with these medicines?		
English Text: Did (you/SP) get treated with these medicines?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	4	4	HCQ150
2	No	8	12	
7	Refused	0	12	HCQ150
9	Don't know	0	12	HCQ150
.	Missing	66	78	

HCQ140A		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		Not treated: unpleasant side effects		
English Text: Why did (you/SP) not get treated? Was it because the side effects to the treatment are unpleasant?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	4	4	
2	No	3	7	
7	Refused	0	7	
9	Don't know	0	7	
.	Missing	71	78	

HCQ140B		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		Not treated: treatment self injected		
English Text: Why did (you/SP) not get treated? Was it because the treatment shots must be self injected?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	1	1	
2	No	4	5	
7	Refused	0	5	
9	Don't know	1	6	
.	Missing	72	78	

HCQ140C		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		Not treated: treatment too expensive		
English Text: Why did (you/SP) not get treated? Was it because the treatment is too expensive?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	3	3	
2	No	3	6	
7	Refused	0	6	
9	Don't know	0	6	
.	Missing	72	78	

HCQ140D	Target			
	B(6 Yrs. to 150 Yrs.)			
Hard Edits	SAS Label			
	Not treated:waiting for better treatment			
English Text: Why did (you/SP) not get treated? Was it because there is a hope of better treatment in the future?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	2	2	
2	No	3	5	
7	Refused	0	5	
9	Don't know	1	6	
.	Missing	72	78	

HCQ140E	Target			
	B(6 Yrs. to 150 Yrs.)			
Hard Edits	SAS Label			
	Not treated: some other reason			
English Text: Why did (you/SP) not get treated? Was it because there is some other reason?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	5	5	
2	No	3	8	
7	Refused	0	8	
9	Don't know	0	8	
.	Missing	70	78	

HCQ150		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		Did doctor limit alcohol?		
English Text: Did (your/SP's) doctor or health professional tell (you/him/her) to avoid or limit alcoholic beverages (in the future) because of (your/his/her) hepatitis C?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	Yes	15	15	
2	No	1	16	
7	Refused	0	16	
9	Don't know	0	16	
.	Missing	62	78	

HCQ160		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		T/F: infection is permanent		
English Text: If someone is infected with hepatitis C virus, they will most likely carry the virus all their lives.				
English Instructions: We would like to know what you have learned about hepatitis C. Please tell me if you believe the following statements are true or false, or if you don't know whether they are true or false.				
Code or Value	Description	Count	Cumulative	Skip to Item
1	True	27	27	
2	False	5	32	
7	Refused	0	32	
9	Don't know	2	34	
.	Missing	44	78	

HCQ170		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		T/F: HepC stops liver		
English Text: Infection with the hepatitis C virus can cause the liver to stop working.				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	True	32	32	
2	False	0	32	
7	Refused	0	32	
9	Don't know	2	34	
.	Missing	44	78	

HCQ180		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		T/F: look and feel fine		
English Text: Someone with hepatitis C can look and feel fine.				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	True	33	33	
2	False	1	34	
7	Refused	0	34	
9	Don't know	0	34	
.	Missing	44	78	

HCQ190	Target			
	B(6 Yrs. to 150 Yrs.)			
Hard Edits	SAS Label			
	T/F: HepC from blood transfusion			
English Text: You can get hepatitis C by getting a blood transfusion from an infected donor.				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	True	32	32	
2	False	0	32	
7	Refused	0	32	
9	Don't know	2	34	
.	Missing	44	78	

HCQ200	Target			
	B(6 Yrs. to 150 Yrs.)			
Hard Edits	SAS Label			
	T/F: HepC from shaking hands			
English Text: You can get hepatitis C by shaking hands with someone who has hepatitis C.				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	True	0	0	
2	False	33	33	
7	Refused	1	34	
9	Don't know	0	34	
.	Missing	44	78	

HCQ210	Target			
	B(6 Yrs. to 150 Yrs.)			
Hard Edits	SAS Label			
	T/F: HepC by kissing infected person			
English Text: You can get hepatitis C by kissing someone who has hepatitis C.				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	True	1	1	
2	False	26	27	
7	Refused	1	28	
9	Don't know	6	34	
.	Missing	44	78	

HCQ220	Target			
	B(6 Yrs. to 150 Yrs.)			
Hard Edits	SAS Label			
	T/F: HepC from infected sex partner			
English Text: You can get hepatitis C by having sex with someone who has hepatitis C				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	True	23	23	
2	False	7	30	
7	Refused	1	31	
9	Don't know	3	34	
.	Missing	44	78	

HCQ230		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		T/F: HepC from birth, infected mother		
English Text: You can get hepatitis C by being born to a woman who had hepatitis C when she gave birth.				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	True	22	22	
2	False	3	25	
7	Refused	1	26	
9	Don't know	8	34	
.	Missing	44	78	

HCQ240		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		T/F: HepC from sharp instrument		
English Text: You can get hepatitis C by being stuck with a needle or sharp instrument that has hepatitis C infected blood on it.				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	True	34	34	
2	False	0	34	
7	Refused	0	34	
9	Don't know	0	34	
.	Missing	44	78	

HCQ250		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		T/F: HepC from coworkers		
English Text: You can get hepatitis C by working with someone who has hepatitis C.				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	True	5	5	
2	False	27	32	
7	Refused	1	33	
9	Don't know	1	34	
.	Missing	44	78	

HCQ260		Target		
		B(6 Yrs. to 150 Yrs.)		
Hard Edits		SAS Label		
		T/F: HepC from injecting drugs		
English Text: You can get hepatitis C by injecting illegal drugs, even if only a few times.				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	True	31	31	
2	False	2	33	
7	Refused	0	33	
9	Don't know	1	34	
.	Missing	44	78	

HCQ270	Target			
	B(6 Yrs. to 150 Yrs.)			
Hard Edits	SAS Label			
	Main respondent			
English Text: Who was the main respondent for the questionnaire?				
English Instructions:				
Code or Value	Description	Count	Cumulative	Skip to Item
1	SP	34	34	
2	Parent/guardian	0	34	
3	SP and Parent/guardian	0	34	
.	Missing	44	78	